

## Articles

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# Patients' Understanding and Use of Advance Directives

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The Patient Self-Determination Act was implemented in December 1991. Before and after its implementation, we used a structured interview of 302 randomly selected patients to determine their awareness, understanding, and use of advance directives. Implementation of the Act did not have a major effect on these. Although more than 90% of patients were aware of the living will, only about a third selected the correct definition or the correct circumstances in which it applied, and less than 20% of patients had completed one. About a third of patients were aware of a Durable Power of Attorney for Health Care and chose the correct definition, and about half identified the correct circumstances in which it applies; less than 10% had completed such a document. Surprisingly, patients who said they had completed advance directives did not demonstrate better understanding of these documents.

Our results indicate that many patients, including some who have completed advance directives, do not fully understand them. It may be unwise to regard these documents as carefully considered, compelling statements of patients' preferences. Appropriate responses to our findings include increased public education, revising state statutes to bring them into congruence with public perception, and expanding the dialogue between physicians and patients.

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**T**he Patient Self-Determination Act of 1990 is a public policy intended to inform patients about some of the steps they can take to exercise control over their medical care if they become incompetent or unable to express their wishes.<sup>1</sup> The Act, implemented December 1991, requires that health care institutions inform all adult patients about the relevant state laws and hospital policies that apply to advance directives. Advance directives such as the Living Will and Durable Power of Attorney for Health Care putatively enable patients who wish to exercise control over their future health care to do so. The Patient Self-Determination Act also requires that hospitals inquire whether the patients have completed advance directives.

The Utah Personal Choice and Living Will statute specified, as do the statutes of 44 states, that a living will applies only when the person who completed it is incompetent and terminally ill. The Utah statute required that artificial nutrition and hydration be administered to patients who have a living will, unless they specifically noted that they refused this treatment. The statute allows a person to appoint someone to make medical decisions for him or her if the granter of this durable or special power of attorney for health care becomes incompetent.<sup>2</sup>

In the relatively short period of time since advance

directives have been available, several studies have investigated patients' attitudes about them.<sup>3,4</sup> Patients appear to be receptive to questions about their preferences for medical care, and they seem attracted to the concept of a document that would ensure that their preferences would be honored. On the other hand, few patients—less than 15% in most studies—have actually completed a living will.<sup>4,5</sup> Few studies have investigated how many patients have designated a durable power of attorney for health care, but the highest estimates do not exceed 15%.<sup>5</sup>

No studies have deeply probed patients' knowledge about advance directives. We used extended structured interviews that included clinical vignettes to investigate how well patients admitted to a hospital understood advance directives. We examined the effect of the implementation of the Patient Self-Determination Act on patients' understanding and use of advance directives. We found that patients' understanding of these documents, especially the living will, was poor and not improved by the implementation of the Act. We propose several steps that could ensure a better match between end-of-life care and patients' preferences.

## Patients and Methods

At the LDS Hospital, Salt Lake City, Utah, the Patient

Self-Determination Act was implemented by providing all patients a one-page summary of state statutes and hospital policies regarding advance directives. Patients' primary care nurses ask patients if they have completed an advance directive.

For this study we planned to complete interviews with at least 200 persons before the Patient Self-Determination Act was implemented and 100 afterwards. We conducted bedside interviews with randomly selected patients admitted to LDS Hospital, a 500-bed acute-care hospital. The interviews were obtained from August 12 to November 22, 1991, before implementation of the Act, and from February 24 to May 15, 1992, after the Act was implemented. The interviews were conducted by trained personnel of the Division of Medical Ethics.

The questionnaire was designed to assess patients' awareness and understanding of a living will and of a durable power of attorney for health care. We asked patients to choose the definition for each document from a list of seven choices (Figure 1), to identify the clinical circumstances in which each document applies, such as incompetence, terminal illness, or both, and to determine the effect of each document in a series of clinical vignettes. We also inquired whether the patient had completed either or both of these documents. The interview required about half an hour to conduct. The questionnaire was pretested and revised to ensure the greatest possible clarity.

To be eligible for this study, patients had to be admitted within the previous 48 hours and to be 18 years of age or older. Starting at the top of a computer-generated random list of eligible patients, interviewers investigated if

What do you understand a Living Will is? [Same question and choices for Durable Power of Attorney for Health Care]

- A document that says how your money and property will be distributed after you die
- A document that says how your body should be handled if you die
- A document that specifies what life-sustaining treatment you don't want if you have a terminal illness and are unable to communicate
- A document that authorizes someone else to act for you in financial and other personal matters
- A document that specifies who should make medical decisions for you if you are unable to do so
- A document that says you are willing to donate your organs if you die
- A document that specifies a way you can give money to someone or an institution and receive a tax benefit
- Don't know
- Other

**Figure 1.**—Shown enclosed in the box is the question patients were asked to indicate their understanding of a living will or a durable power of attorney for health care.

**TABLE 1.**—Percentage of Patients Who Are Aware of and Who Understand Advance Directives Before and After Implementation of the Patient Self-Determination Act (PSDA) (n=302)

Awareness and Understanding	Advance Directives			
	Living Will		Durable Power of Attorney	
	Before PSDA (n=202), %	After PSDA (n=100), %	Before PSDA (n=202), %	After PSDA (n=100), %
Awareness .....	91	94	32	39
Chose single correct definition .....	31	41	29	37
Chose correct circumstance(s).....	28	32	46	54

the patient was available to be interviewed and if the patient, as judged by his or her nurse, was mentally and medically able to participate in the study. Patients were eligible to be interviewed regardless of the acuity of their illness or unit to which they were assigned. Patients who did not speak English were not interviewed. Available patients deemed capable were approached and asked if they would consent to be interviewed. Midway through the interview, patients were asked if they wished to continue.

Factors associated with answers to questions and the completion of advance directives were statistically analyzed using  $\chi^2$  and Fisher's exact test.

## Results

Before our hospital implemented the Patient Self-Determination Act, we completed interviews with 202 of 361 (56%) patients that we approached. Afterwards, 100 of 195 patients (51%,  $P =$  not significant [NS]) completed the interview.

Our study population, 41% male, with a mean age of 48 years, did not differ significantly from the inpatient population during the interview periods. Like the patients at our hospital generally, our subjects were predominantly white, and 48% said they belonged to the Latter Day Saints religion. Most of our interviewed patients (91%) had graduated from high school; 68% had some additional education, and 29% had completed four or more years of higher education. Patients in the two parts of our study did not differ significantly with respect to the above factors.

Table 1 shows awareness and two levels of understanding of living wills and durable powers of attorney for health care by our study subjects. There were no significant differences after the Patient Self-Determination Act was implemented. When asked to define only a living will or a durable power of attorney, 10% and 2%, respectively, of patients chose to define both documents. Only 6% of patients in both periods selected the correct definition and identified the clinical requirements for both types of advance directives. The 30 patients who correctly answered these questions about the living will were not significantly different from patients who answered incorrectly with respect to sex, age, religion, or race. They were more likely, however, to have finished high school (100% versus 89%,  $P < .05$ ). The 41 people who answered these questions accurately about the durable power of attorney

TABLE 2.—Percentage of Patients Who Correctly Indicated the Effect of an Advance Directive in a Paradigmatic Case, or a Case That Involved a Persistent Vegetative State (PVS)

Patient Self-Determination Act Implemented	Patients Understood Effect of Advance Directives, %			
	Living Will in Paradigm Case	Living Will in PVS	Durable Power of Attorney in Paradigm Case	Durable Power of Attorney in PVS
Before Act (n = 202).....	50	24	75	71
After Act (n = 100).....	58	16	76	78
Significance, P.....	NS	NS	NS	NS

NS = not significant

differed from those who answered incorrectly by age (76% versus 47% were younger than 51,  $P < .001$ ), and they were also more likely to have finished high school (100% versus 88%,  $P < .05$ ), but they did not differ significantly by sex, religion, or race.

Most patients who had heard of advance directives reported that the media was the source. Less than 10% said they heard about them from a physician or nurse. During the second study period when written information about advance directives was given to patients by the hospital, 24% and 16%, respectively, recalled receiving that information about the living will and durable power of attorney.

We also assessed patients' understanding of advance directives with clinical vignettes. In one vignette, a paradigmatic case, "The patient has cancer, cannot communicate his or her wishes, and is expected to die within one month. The patient has respiratory failure and will die sooner unless a ventilator is used."

In a second vignette, "The patient has been in an accident and is now in an irreversible coma (persistent vegetative state). Nutrition and hydration (food and water), delivered intravenously or by a tube inserted into the stomach, are necessary for survival."

Table 2 shows the proportion of patients who correctly indicated the effect of each advance directive in these cases. Notably, about 80% of patients made an incorrect choice about the effect of a Utah living will in the case of the patient in a persistent vegetative state: 44% indicated that the living will would prevent the provision of nutrition and hydration, 11% thought the living will would require these measures, and 22% said they did not know the effect of the living will in this case. Only 21% chose the correct answer, namely, that the living will did not apply in this case because the patient was not terminally ill.

Before the Patient Self-Determination Act was implemented, 15% of our subjects reported completing a living will and 5% a durable power of attorney for health care. Afterwards the proportions were 18% and 7%, not a significant change. Of the 48 patients who said they had a living will, 16 said they also had a durable power of attorney. Two other patients reported that they had only a durable power of attorney.

Although Table 2 includes the answers of all the respondents to our survey, we separately examined the responses of patients who reported that they had completed either a living will, a durable power of attorney, or both. When we examined the demographics of these patients

and those in our survey who had not completed such documents, we found that patients with living wills were significantly more likely to be older than 51 years than those without them ( $P < .001$ ). These patients were also significantly more likely to have graduated from high school (98% versus 89%,  $P = .04$ ) and to have completed additional years of education ( $P = .03$ ). We noted no significant differences between those patients who reported completing a durable power of attorney and those who did not, although those with the document were more likely to be older than 51 years.

Surprisingly, patients who said they had completed a living will did not understand this document's definition or clinical application better than patients who said they had not completed one. Of the 48 patients who reported having such a document, 16 (33%) identified the single correct definition, and 19 (40%) correctly identified the circumstances in which the Utah Living Will applied. Presented with the paradigmatic vignette, living will holders did not perform better than those without the document ( $P = NS$ ). Of the 48 patients, 35 (73%) correctly said that it would prevent the use of a ventilator.

When presented with the vignette about a patient in a persistent vegetative state, in which the Utah Living Will would not apply, living will holders again did no better than those without the document ( $P = NS$ ): 31 (65%) said the living will would prevent health care professionals from providing nutrition and hydration, 9 (19%) correctly said the living will does not apply, 6 (12%) said they did not know, and 2 (4%) said the living will would require artificial nutrition and hydration.

Like the patients who had completed a living will, most patients who had completed a durable power of attorney for health care did not have a significantly better understanding of the definition of the document or the circumstances in which it applies than the rest of the surveyed population. Of the 18 patients who said that they had appointed a proxy for health care decisions, 4 (22%) chose the single correct definition, and 9 (50%) correctly identified the circumstances in which a durable power of attorney applies. When presented with the paradigmatic vignette, 15 (83%) indicated correctly that the proxy had the legal right to decide about the use of a ventilator.

We asked patients whether a living will or durable power of attorney, as the final expression of their wishes, should be the determinant of their care. We asked them under what circumstances the preferences expressed in a living will or by an appointed proxy should be overridden. Their responses are shown in Table 3. These responses did not change significantly between study periods. Remarkably, a similar proportion of patients who said they had executed an advance directive, which is legally binding, said that it should be overridden.

## Discussion

Before drawing conclusions from our study, certain limitations must be acknowledged. Interpreted as a response rate, the 55% of patients who completed the interview would appear to be a rate that could provide results

TABLE 3.—Patients' Opinions About Overriding Advance Directives

Advance Directive	Should Directive Be Overridden?								
	All Respondents (n=302), %			Patients With Living Wills (n=48), %			Patients With Durable Powers of Attorney (n=18), %		
	Yes	No	Not Sure	Yes	No	Not Sure	Yes	No	Not Sure
<b>Living Will</b>									
Physicians should ignore living will instructions if they think to do so is best for the patient .....	20	63	17	17	71	12			
Physicians should ignore living will instructions if family members ask them to..	19	66	15	23	73	4			
<b>Durable Power of Attorney</b>									
Physicians should ignore proxy's instructions if they think to do so is best for the patient .....	21	53	26				0	78	22
Physicians should ignore proxy's instructions if family members ask them to..	20	55	25				17	72	11

representative of a population if there were no systematic and confounding reasons for refusing to participate. We asked patients why they refused and were given a variety of reasons including discomfort, the presence of visitors, anxiety, fatigue, and a lack of interest in participating in such a survey. It is unlikely that patients refused to be interviewed because of their extensive knowledge about advance directives. Thus, it seems that our interviewed sample was not likely to underestimate the level of knowledge in our hospital population. Certainly a survey in a single hospital, particularly with a population that is primarily white and well educated, cannot be assumed to be representative of the knowledge and opinions of other segments of the American population. Each of these possible biases in our sample would seem to suggest, however, that our results would overestimate rather than underestimate the level of understanding of advance directives in the rest of the population. Although we interviewed patients in only one hospital, our patient group was more inclusive with respect to age than those in other studies of patients' knowledge about advance directives.<sup>4</sup> Although a higher proportion of our patients were members of the Latter Day Saints religion than might be found elsewhere, we did not find religion to be a significant factor with respect to awareness, understanding, and use of advance directives. The correctness of our patients' answers was judged with respect to the Utah Personal Choice and Living Will statute as of 1992. Patients in other states may be more or less knowledgeable about their state's laws, or the statutes may be more aligned with public perception (or both).

Our study differs from others in that we assessed the knowledge of adult patients of all ages, but who had a common characteristic, namely a need to be in the hospital. Thus, although our sample is obviously different from a random sample of the United States public, a healthy population, nursing home residents, or a group selected based on being older than 65, patients in our study certainly had a reason to be concerned about and affected by decisions regarding their health care. In a survey of pa-

tients admitted to a tertiary care hospital such as ours where many admissions are anticipated and elective, we might expect to have encountered a higher proportion of patients who had completed advance directives than was found to be the case. We did find, as did other investigators, that patients are generally aware of advance directives,<sup>4,5</sup> but the level of patient knowledge and understanding remains poor.

There are several other possible limitations to consider because the number of persons in our survey who had actually completed a living will and, particularly, a durable power of attorney was relatively small. Therefore, it may be premature to conclude that patients who have completed these documents do not differ significantly in their knowledge about them from patients who have not done so. Our interview subjects did not include patients who were unconscious, unable to communicate, or incompetent. These are the patients for whom advance directives might be useful. We have no information on the frequency with which these persons had previously executed advance directives or their knowledge about them. The competent patients we did talk with were obviously in an environment that could be stressful, and the accuracy of their answers may have been adversely affected by that. We also did not insist that patients who reported completing advance directives produce copies of them.

Despite these possible limitations, it appears that a significant proportion of the patients admitted to our hospital do not understand our state's advance directives very well. Implementing the Patient Self-Determination Act through a relatively passive program of distributing written information about advance directives has done little to improve patients' understanding. In our hospital, the Act has had little discernible effect on the low rate at which patients complete advance directives.

An unexpected result in our study was that even patients with advance directives frequently misunderstand them. Like patients without living wills, patients with them often failed to recognize the requirement for a terminal condition. Perhaps more surprising was that a sig-

nificant minority of patients who had executed advance directives thought they should be overridden if physicians or family members thought it best to do so.

Completing an advance directive did not seem to increase patients' knowledge about the document, but it may have had a benefit for these persons independent of the document's effect on medical decisions. The act of completing the directive may lower a patient's level of anxiety about death and the treatment associated with the end of life. That result has been suggested by the study of Henderson.<sup>6</sup> Our impression, as we interviewed these patients, was that they were proud and somewhat relieved that they had taken steps that they felt would control their care in circumstances in which they viewed a lack of control as frightening and burdensome. Completing a living will is unlikely to provide the kind of control they wanted in one of the circumstances they feared most.

When we recognized the discrepancy between patients' perceptions about the Utah living will and the statute, particularly with respect to the persistent vegetative state, we shared our findings with state legislators. They chose to amend the statute and include persistent vegetative state as an additional criterion that would make the living will operative.<sup>7</sup> This certainly will help some patients realize their expectations of end-of-life care. What remains unresolved, however, is the apparent paradox that a substantial minority of patients want their final expres-

sions of personal preference to be overridden if their physician or family thinks it best to do so.

At this point then, despite the Patient Self-Determination Act, health care professionals are still likely to find that most patients who face end-of-life decisions have not completed advance directives. Even if patients have completed advance directives, clinicians should recognize that the directive(s) may be neither complete nor thoroughly understood expressions of patients' preferences. To encourage patients to complete advance directives without extensive education and counseling, or to strictly adhere to all advance directives without discussion, is unlikely to serve patient autonomy fully. Discussion with all patients before a crisis still seems the best way to ascertain patients' values, preferences, and goals for therapy.

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